

**Tiger Team
Draft Transcript
September 24, 2010**

Presentation

Erin

Good afternoon. This is the Health IT Policy Committee Meeting of the Privacy and Security Tiger Team. As a reminder, this is a public call and there will be an opportunity at the end of the call for the public to make comments.

First to begin, we'll do a quick role call. Deven McGraw?

Deven McGraw – Center for Democracy & Technology – Director

Yes. Here.

Erin

Paul Eggerman?

Paul Eggerman – eScription – CEO

Yes.

Erin

Dixie Baker?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Here.

Erin

Christine Bechtel?

Christine Bechtel – National Partnership for Women & Families – VP

Here.

Erin

Rachel Block?

Rachel Block – New York eHealth Collaborative – Executive Director

I'm here.

Erin

Carol Diamond?

W

Carol will be on in a moment. She's on another call right now.

Erin

Okay. Judy Faulkner?

Judy Faulkner – Epic Systems – Founder

Here.

Erin

Gayle Harrell? John Houston? David Lansky? David McCallie?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Here.

Erin

Wes Rishel?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'm here. You might ask the typer to put their phone on mute.

Deven McGraw – Center for Democracy & Technology – Director

Yes and the person in the cave, too.

Erin

Micky Tripathi?

Micky Tripathi – Massachusetts eHealth Collaborative – President & CEO

Here.

Erin

Latanya Sweeney? Did I miss anyone?

Neil Calman – Institute For Family Health – President & Cofounder

Yes. This is Neil Calman. I'm here.

Deven McGraw – Center for Democracy & Technology – Director

Oh, great!

Paul Eggerman – eScription – CEO

This is Paul Eggerman, thanking in request.

Deven McGraw – Center for Democracy & Technology – Director

Way to go, Paul!

Joy Pritts – ONC – Chief Privacy Officer

This is Joy Pritts. I'm on for probably about 10 or 15 minutes and then I have to jump off and will return later in the call.

Adam Green – Progressive Chain Campaign Committee – Cofounder

This is Adam Green. I'm on.

Erin

So with that, I'll turn it over to Deven and Paul.

Deven McGraw – Center for Democracy & Technology – Director

Welcome, everybody, to our first public meeting. We had an administrative call to work on scheduling issues a week ago, but now this is really our first substantive meeting post the provision of our summer recommendations to the Policy Committee back in August. So we're diving back in, in earnest here, and we're glad that so many of you were able to join us. I know that Gayle Harrell is expected, but she's just going to be a little bit late.

So, why don't we move to the agenda slide, which is the next one, so you get a sense of what we're trying to tackle today. We're going to spend a little bit of time up in the front of the call taking a look at a draft framework, which is going to be a document that we're using really as a tool for both the Tiger Team members as well as the public to get a set of where each of our recommendations fit within and the progress that we're making to achieve a comprehensive framework of privacy and security protections

that flesh out the data sharing principles that have already been adopted by the Policy Committee and adhere to technology principles as well that the Standards Committee has endorsed. So, we'll talk a little bit about that. We're not going to spend a lot of time on it, only because it's really more of a tool for us to use moving forward as we tackle each of the issues that we're focusing on in some more depth. But I want to make sure people understand what it is, how we intend to use it, and get any relevant comments from you all on how to improve it, etc.

Then we will move to the issue that we want to spend most of the call focusing on today, which is openness and transparency and fleshing out a framework on that particular principal. We'll start with the MITRE Team who is back on board and helping us, for those of you who didn't hear about on our administrative call. They're going to go over a little bit of background here, some of the HIPAA Privacy Rules. Of course, we have Adam on the phone, which is great, keeps us honest, makes sure we do this right. Then think about some key considerations of, in particular, our reliance on, historically in the law, of a paper notice to patients, is the way that they get informed about data uses and disclosures, and then what the assumptions are.

As usual, we try to start with some assumptions that will enable us to focus our discussion a little bit better. In the past we've done so by specifically focusing on the exchanges for stage one of meaningful use. I think that while that is constraining in many ways, it does help us at least get started in thinking about these issues and, as you'll see, we're going to start with that initial frame, even in our discussion today, although I'd like for us, in this next phase of our work, to continue to—as we are able to come to conclusions about something, for example, on openness and transparency, a set of recommendations that work well for provider exchange for stage one of meaningful use—to try to push on those a little bit and think about other contexts of exchange and how those recommendations might be applied in that context. But it always helps with the more narrow frame and then expand outward.

We will then move, after we do some background, to some questions that we've teed up to try to get to consensus on some recommendations on this topic. Then at the very end of the call, we'll talk a bit about what we've got on deck for the next meeting, and then of course, open it up for public comment.

Paul, did you have anything you wanted to add before we jump into this and then we'll see if anybody else from the Tiger Team has any questions?

Paul Eggerman – eScription – CEO

First, I just want to thank everybody for their continued participation in our Tiger Team. We went through a very intense process over the summer and we pushed everybody very hard with meetings twice a week and long meetings. The results were really quite good in terms of what we produced. As a result, the ONC has asked us to address several more issues. But we will be addressing them with a little less intensity moving forward.

At the same time, we want to keep the same ground rules, which were to stay focused on the topic. Let's not use these public meetings to try to wordsmith minor issues, although we will have more time between meetings now so there will be opportunities to do a lot of e-mail exchanges to make sure we get the wording correct on whatever documents we produce.

But today's topic is very interesting: transparency and openness. So we want to make sure that patients are fully informed about what's happening with their information, but we want to do it in a way that's not annoying to the patients with paperwork and is not burdensome to providers. So those are interesting challenges. So we're going to start with some background material. First we'll do the privacy security framework, and then we'll do some background material, then we'll launch into the questions.

Deven McGraw – Center for Democracy & Technology – Director

Does anybody on the team, before we launch into the framework, have any questions about the agenda? Okay, terrific. That was the easy part.

Let's move to the next slide, which really has nothing on it. I think it's the placeholder for the framework. So, you all received in your e-mail a draft, policy and technology framework for information exchange. It's not critical if you haven't had a chance to read this before the meeting today. Again, this is not a document that we're asking for a final stamp of approval for language on. As I mentioned in my introduction, this is really a tool for us to keep us on track, and it's for both us to use as well as for the public to see the progress that we're making.

In many ways, it reminds us that our goal here is not to just come up with a set of answers to some specific questions, but to build out a comprehensive framework or a comprehensive set of policies and technology requirements that really fill the gaps that we think might exist in current law and that fully implement in an effective way the policy principles that are really on the first page of this framework document. Again, these are the ones that are the core, overarching principles that the Policy Committee adopted and that are actually part of the strategic plan document that the Policy Committee also endorsed.

For many of you, just so you know, we started an exercise to build out a framework that looked like a chart. You'll remember that from the very early stages of the Tiger Team where we were working on populating that with issues and questions, even as we were trying to, as a Tiger Team, drill down on the specific issues that ONC had asked us to focus on over the summer. So for those of you who were able to look at that initial framework document that we had circulated early on in our Tiger Team, this should look very familiar to you. Essentially we tried to find—MITRE, actually, helped us—find a much more effective format, I think, for this.

First of all, you've got the policy principles that are from the nationwide data sharing framework that the Policy Committee has already adopted. We have these nice bubbles across the top with each of the key elements, and then a little more detail that follows in the text below it. T

hen on page two of this framework, you've got essentially the technology principles that were adopted by the Standards Committee.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Are we supposed to be seeing this on the screen?

Deven McGraw – Center for Democracy & Technology – Director

No, because it's not in slide format, Wes.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Oh, okay.

Deven McGraw – Center for Democracy & Technology – Director

If you look in the download section to the left, it says Policy Framework. You also should have received it in your e-mail yesterday.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes. I guess I wasn't paying attention. I'm sorry.

Deven McGraw – Center for Democracy & Technology – Director

No, that's okay. I doubt you're the only one, Wes. I'm just going through the overall structure of this thing, so people get a picture of what it is and a clear understanding of how we intend to use it. So hopefully, this won't be too confusing for those of you who are sitting in cars and on cell phones and don't have a document in front of you.

So again, it's also got, on the second page, the technology principles that were adopted and some— So really, these first two sets of pages are sort of our touchstone or the reminder of the overarching principles that guide our work, both with respect to policy and technology.

Then on each of the subsequent pages of this framework, the principles are laid out in a little bit more detail. So if you see on Individual Access, which is the first one, you've got sections for what's already in current law. You've got sections for technology implications. What are the certification criteria, for example, for EHR technology that have already been adopted? But there are lots of empty boxes, and this is where the use of this as a tool is really evident.

The idea is that what we're doing as a Tiger Team is fleshing out with our recommendations what ought to happen from a policy and technology standpoint in order to actualize or realize the principles that we have already adopted. So there's a big empty space in individual access, as a matter of fact, for the Tiger Team recommendations because we haven't really touched on this issue yet. I've got, as a placeholder in there, that we have slated this as a topic for discussion on our call on November the 22nd.

Then, the Notes and Consideration column at the bottom is just taking out the material that those of you Tiger Team members who had an opportunity to read through that earlier version of this framework and who added some notes and questions and comments, all of that is in this section below. So, that really just reminds us of whether there are resources we should look to, questions that we might need to answer. It's this column in particular that, if you wanted to spend some time with this framework and think about how everything fits together in a big picture and questions occur to you, you would write them in this section and feel free to send them to us offline.

Otherwise, the way that I think we will use this most effectively is, throughout our meetings together and our convening's and our discussion, to flesh this out with our recommendations. So it will help us to see where our recommendations fit in with the other recommendations that we've made, to see which policy principles that each of our recommendations implement, and similarly, it will show the public that as well and it will also help show us where the gaps are.

So it's not hard to see, for example, we've made some progress on collection use and disclosure limitations because we had a lot of recommendations in our letter to the Policy Committee over the summer but, as I mentioned for individual access, there's a big open box there and some gaps that we need to fill with respect to correction of the record in the event of any errors. Openness and transparency have got some information on it, but it's more related to transparency among providers and their business partners than it is about transparency to patients, and that's the topic that we're taking up today.

So, unlike the other framework document where there wasn't as much time to use it as a working tool and a working document going forward, I really think it's helpful for us to rely on it in a more consistent way going forward into the future. Again, I think it continually helps place what we're doing into a larger frame, and keeps things from dropping off the plate in terms of the gaps we need to fill, and presents to the public, I think, an overarching vision for what we're trying to achieve.

So I'm going to stop and see if folks have questions about this.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

This looks like really great work. I'm looking forward to really looking at it more carefully. The question I have is the column that's labeled Accountability and Oversight— When I first saw it, I thought that must be equivalent to what the Governance Workgroup is now doing. Is that equivalent to Governance?

Deven McGraw – Center for Democracy & Technology – Director

That's a good question, Dixie. I think that whatever Governance is doing is clearly a piece of all of this. They're still working on their recommendations and there's a hearing scheduled for next week. I think that in my view there are lots of tools and levers for accountability, of which enforcement of law would be one. Enforcement of contractual obligation is another. There's really a constellation of levers there and certainly, I think the Governance Workgroup is looking at what other policy levers beyond the ones that we already have; meaningful use criteria and certification conditions are another policy lever.

So I think for use to populate this chart, especially in the absence of anything more specific from the Governance Workgroup, I think we use what we have. Where we think there are not sufficient policy

levers that exist within ONCs current toolbox, then I think that we make recommendations in that regard as well. So I think that you are right, but I don't think it hamstrings us from populating that piece of the chart for the issues that come up. Does that make sense?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes, sort of. The reason I really brought it up is that some of the things that are in that column now appear to be what Governance should be overseeing but are not governance mechanisms or enforcement mechanisms in and of themselves. I really would hope that the Governance Workgroup would be looking at the same thing we are and realizing where these empty spaces, as you point out, exist in that column.

Deven McGraw – Center for Democracy & Technology – Director

Well, they're more than welcome to help with the use of this chart.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I guess I'm one of the overlap members between Governance and this. One of the reasons I asked last week that this be put together—and I want to echo what Dixie said. I think it's a lot of great work and it's serving its purpose already, which is to show some empty spaces and even some spaces that have some text in them, but there's still stuff to do in those spaces—one of the reasons I asked for this though is because I didn't want, on the Governance side, to have to re-invent the other policy elements there. We wanted to be able to sort of use this and then look at accountability and enforcement oversight as one element of governance, and see how and where it lines up with the existing framework and where there are gaps.

So, long way of saying ... exactly the purpose, Dixie, so I hope that the crosstalk between the two groups continues to be as productive.

Deven McGraw – Center for Democracy & Technology – Director

Any other questions from folks? Of course, this is not your only opportunity to provide feedback. I get it that a lot of you may not have had a chance to look at this at all and it's entirely possible that the last five minutes were just completely lost on you because without the chart in front of you, it's really hard to understand what we're talking about. So, feel free to weigh in with questions or comments when you finally do get a chance to look through it.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I just want to make one more comment, which is the converse—I don't know if it's the converse, but it is also true that while there's existing law on Tiger Team recommendations for a lot of these elements, there are other areas or places or policy making bodies that exist both within government and outside of government that we need not complicate this with, but I just want to flag it because it's part of what I think the whole governance exercise has to take into account. So, individual access or enforcement of individual access or enforcement of policies on the internet for personal health record services, etc. may not all come from the frame that we're currently looking at. There are other bodies of government in other areas that apply to that.

Deven McGraw – Center for Democracy & Technology – Director

What I think would also be helpful, Carol, is when we are focusing on a particular topic and where there are other efforts that are relevant, that have some accountability mechanism associated with it, it would be great to surface those as we talk about it. Because I think that it would be—to the extent that there are mechanisms for assuring industry implementation that are not about law necessarily, but are about cooperative agreement or professional certification or other sets of expectations that different entities strive for and that have meaning. I think it's important to include those.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes.

Deven McGraw – Center for Democracy & Technology – Director

Anything else? Alright, terrific. Thank you all. We're going to move on in the agenda to framing the issue that we're going to take up today, which is openness and transparency. Just so that you see that we will be using this framework document on a going-forward basis that would be page five, that we will populate with the results of our recommendations in this area. But we're going to start.

We're going to get back to the slides, so there's no need to worry about whether or not you have the framework in front of you anymore, and allow the MITRE team to go through some background slides for us to set the stage for our discussion. So, Linda, is it you who's going to lead this?

Linda Koontz – MITRE – Principal Information Systems Engineer for Privacy

Yes, it is.

Deven McGraw – Center for Democracy & Technology – Director

Alright. Linda Koontz from MITRE. It's all yours.

Linda Koontz – MITRE – Principal Information Systems Engineer for Privacy

Good afternoon, everyone. We just have a few slides here to remind everybody of the privacy rule requirement concerning openness and transparency, just to tee up the discussion a bit. Slide four is the areas that the notice is required to cover under the privacy rule. I think the main takeaway here is that while in the privacy rule, it requires the notice to include legally permitted uses and disclosures, the notice does not cover what the actual uses and disclosures by the provider are. This might be something that you might want to discuss in your discussions.

On the next slide, this is, again, a reminder of the elements of the privacy rule and these are the different methods by which the provider should make the notice available. The provider is also required to make a good faith effort to get acknowledgment in writing from the patients as the receipt of the notice.

Deven McGraw – Center for Democracy & Technology – Director

So that's the HIPAA notice that people sign, right?

Linda Koontz – MITRE – Principal Information Systems Engineer for Privacy

Absolutely. The HIPAA notice that people sign, or sometimes referred to as the NPP. The main part of this slide is some of the key considerations for ensuring openness and transparency. What we have here is a list of examples that we pulled from various sources as to what the elements could be of a notice. This is certainly not exhaustive by any means, and it's not to represent anything in terms of what should be included, but it's perhaps a way to sort of stimulate some discussion and maybe be food for thought as we move forward.

Christine Bechtel – National Partnership for Women & Families – VP

For those of us who are mobile, you don't have to read all the slide or anything, but can you give us a little bit more of what's on the slide—just a couple of the examples—I think, would be helpful.

Linda Koontz – MITRE – Principal Information Systems Engineer for Privacy

I'm really sorry. I will go back a couple of slides. I was assuming everybody could see what I was looking at and I didn't want to read to you the slides. I'll be a little more detailed.

The HIPAA Privacy Rule requires that covered entities have to provide a notice of its privacy practices to patients. Basically what happens is that the notice is supposed to cover the legally permitted uses and disclosures, their duties to protect privacy, the patient's rights under HIPAA, and also a point of contact for further information and for making complaints. Again, the point here is that the notice covers the permitted uses, but not the actual uses.

The next slide, we talked about the means by which the notice is to be distributed by the provider and here are just a few examples. For first patient visits, they're supposed to have personal delivery of a paper copy to the patient. There should be automatic and some contemporaneous electronic response if there's electronic service delivery. They're supposed to post the notice at any Websites that a provider

may maintain. They're supposed to post the notice as soon as practical after an emergency treatment. Of course, this applies to everyone on request. A provider must make his notice electronically available too.

They have to make a good faith effort to obtain written acknowledgement and document the reason for any failure to obtain that. The provider is relieved of the need to request acknowledgement in an emergency situation.

Again, some of the examples of elements of notice, I'll just go over these pretty quickly defining what is considered PHI, defining what PHI the provider collects, describing how the provider collects, describing the privacy practices for controlling and for the security safeguards for protecting, providing patient options, disclosing standards, guidelines and regulations and laws regarding the handling of PHI, disclosing who has access, processes for patient redress, a point of contact, of course, and informing patients of their rights under HIPAA.

Deven McGraw – Center for Democracy & Technology – Director

Those again, Linda, were not necessarily components of the law, but different considerations that people have raised as to what makes notice valuable or what it should include.

Linda Koontz – MITRE – Principal Information Systems Engineer for Privacy

We looked at various documents where people had different notions of what constituted best practices in terms of notice. But it's a laundry list of options, to some extent.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I have a question, and maybe we're coming to it, but there's a lot of good discussion here about notice, but I don't see any mention of the accounting for disclosure or extensions that ARRA brings to the table, which ... and modifies. Is that on purpose?

Deven McGraw – Center for Democracy & Technology – Director

I'm suggesting that we not pick that up on this call, part because the parameters on that HHS had issued a request for information and they're currently in the process of doing a rule on that. So, I think because that's an important piece of transparency, but I would love to consider it separately once we have a little bit more information on how HHS intends to implement that with the new set of rules.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Okay, although it makes more sense logically, if we have input on that, to do it before they regulate it rather than after. Or, I know they had their—

Deven McGraw – Center for Democracy & Technology – Director

Yes, but we missed an open comment period.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, I know that's over.

Deven McGraw – Center for Democracy & Technology – Director

Yes. So the ability to— I mean, Adam, I don't know if you want to weigh in on this.

Adam Green – Progressive Chain Campaign Committee – Cofounder

I'll add that we are going to do a notice of proposed rulemaking, which we expect to have a 60-day comment period. So there will be another opportunity after we've actually proposed how we're implementing the HITECH accounting provision.

Deven McGraw – Center for Democracy & Technology – Director

But, Adam, I think David's asking about whether there's an opportunity to weigh in even on your drafting of that proposed rule or did it kind of pass with the RFI? What do you think about that?

Adam Green – Progressive Chain Campaign Committee – Cofounder

It's a work in progress, so opportunity to weigh in is somewhat limited in that respect is all I can really say.

Christine Bechtel – National Partnership for Women & Families – VP

Can you give us any sense of ballpark of if you think the NCRM might come out this year or next year or do we have a sense of timing?

Adam Green – Progressive Chain Campaign Committee – Cofounder

I think I can say this year we're expecting it to come out.

Paul Egerman – eScription – CEO

This calendar year.

Deven McGraw – Center for Democracy & Technology – Director

Yes, since the fiscal year is rapidly drawing to a close.

Paul Egerman – eScription – CEO

Six days left.

Deven McGraw – Center for Democracy & Technology – Director

Well, that's helpful. Thank you, Adam. It's also an incredibly contentious issue and it's not as though I don't think that it's not a worthwhile topic. Given potentially limited opportunities to weigh in at this stage and some other progress that I'm thinking or at least hoping we can make on transparency outside of that accounting on this call, I'd like to parking-lot it.

So I think we're moving on to setting the stage for the discussion that we do hope to have today and I'm going to turn it over to Paul to lead us through the next set of slides.

Paul Egerman – eScription – CEO

Yes, I'm just going to quickly review with everybody, remind everybody, the scope of what we're trying to do. On the slides here, you have on the right a picture of what appears to be a provider and patient relationship. We're going to focus on the provider-patient relationship. On the left, you have what I call this atomic view of stage one of meaningful use where you have health information exchange in the center and these, sort of, things circling around it. But the main concept is basically information for patient treatment which is really, in stage one, a patient summary document. There is also some public health reporting and some quality reporting.

The purpose is just to remind you that that's really all that is our focus. Also our focus, to be clear, is on information exchange, so even though we've got this picture of a patient-provider, we're really not talking about privacy and security issues within an organization. In other words, we're not talking about one physician who works with another physician within the same group practice or the same entity. We're talking about when information gets transmitted from one organization to another. So that is the scope of our effort.

We also want to remind you first of a core value that we described in the letter and sort of guiding a lot of our work. We had this core value that we must consider patient needs and expectations. We said patients should not be surprised about or harmed by collections, uses, or disclosures of their information. So that's an important concept if we talk about transparency. Transparency is all about what does the patient know and they should not be surprised.

We also made this other recommendation that is listed here. It's really not a transparency recommendation, but it's important to keep in mind. We did say that third party service organizations, which really predominantly, we were thinking about these HIO organizations, in the business associate agreement, they have to describe all of their uses of information including use of de-identified data. Again, that's not transparency because it's really talking about how various business associates provide

information to each other, but it does say that at least in theory, providers have information about what is happening to the data that they provide to these organizations.

Deven McGraw – Center for Democracy & Technology – Director

Right. I mean, one could think it's transparency amongst the trading partners, but not transparency of the patient.

Paul Eggerman – eScription – CEO

Yes. But what we're talking about today is really transparency to the patients. That's really the issue. So we have these five questions that we're going to try to ask you to respond to this afternoon, if we can get through all of them. This first one is to what extent—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Paul, could I just make a quick comment? On this issue of transparency to the trading partner versus transparency to the patient, it would be virtually impossible for the physician to be transparent to the patient if we didn't have this transparency to the patient to the trading partner, being a physician. So it really is quite closely related to the topic at hand.

Paul Eggerman – eScription – CEO

Yes, you're right. It's foundational. In other words, because that's in place as I said, in theory, the provider, the physician has the information they need to transmit to patients, so that it is sort of an important foundational element. So that is a very good point, Wes.

Neil Calman – Institute For Family Health – President & Cofounder

Can I just ask a question before you go on? Just this business of informing patients, it's possible that this is in the ... process, right? So people get informed at what point of time in terms of the uses of their data, but then a provider a year later decides that there's some other use of the data that they're contemplating or they're doing. So I think we also need to think about some sort of change process here. What happens if that changes along the line? Does that mean that every single person that's been seen has to re-consent to a new process? I just want to make the point that I don't think this is As this stuff evolves and the data uses evolve, it's very possible that those consents become sort of obsolete.

Paul Eggerman – eScription – CEO

Excellent point. Two things: One is when you look at the questions, question number four does deal with the frequency of informing patients and notice. The second thing is you used the word consent. Consent is slightly different from this concept of notice. Consent is patient's permission and we described circumstances under which you had to get permission from patients.

This is ... discussion about transparency are really a concept of notice. So in this discussion, this is just what patients need to be notified about. So we're not asking for consent, we're just saying what is it that is at least the minimum that providers should be notifying patients about when it comes to healthcare information exchange.

But good point about how it changes, and that's why we have a question on that. Was somebody else trying to ask a question or make a comment? I didn't mean to cut somebody off.

So, these are the five questions. The first one says to what extent should health information exchange practices be disclosed—this is ... use of the word disclosed—to patients. So in other words, to what extent do patients need to be notified about what is the health information exchange practices? Then there's sort of another question that's part of this, which is what about participation in OHCA's, in organized healthcare arrangements, and we'll talk about that when we get to the first question.

The second one says what is the required level of notice and we're talking here about required level. The difference between the first question and the second is in the first question, we're sort of saying, "What do we need to tell patients about?" In the second one, we're saying, "How much detail do you have to tell

them?" In other words, should you tell them about encryption? How far detailed are we supposed to be going?

Deven McGraw – Center for Democracy & Technology – Director

Right or every single possible disclosure or broad categories?

Paul Eggerman – eScription – CEO

Right. So there's a lot of issues there. Third—this question is a very interesting question—is the HIPAA Privacy Rule notice the most effective instrument for ensuring openness and transparency. So this relates to some of these comments that I made in my opening comment. Well, gee, we don't want to be annoying patients with a lot of unnecessary paperwork. We don't want to have administrative burdens placed on providers. But at the same time, we want to be transparent. So, what's the best way to do that?

Fourth question is partly related to the question that Neil just raised ... how frequently do you have to inform patients? Do you have to tell them any time something changes? Do you have to tell them once a year? What's the frequency? The fifth question relates to effectively accounting measuring of openness and transparency.

So these are all actually fascinating questions, and I think unless people have any comments, I'd like to just dive into the first one. Anybody has any comments about these five questions?

So, let's just dive into the very first question: To what extent should health information exchange practices be described to patients? To what extent do patients need to be notified of this? It lists a few policy considerations. Patients ability to understand what PHI exists about them in various databases, how it's exchanged with an HIE, defining HIE models—I don't know if we want to go that far, maybe we do.

Then there's this other issue about participating in an OHCA. If we separate that from the others for a minute, if we think about the involvement with HIEs, picking up on Neil's comment, to remind everyone we did describe consent criteria. Presumably before we're going to ask patients for consent, we're going to tell them something about what it is they're consenting to. So, that might have an influence on how we look at the first three. There's listed on the screen a comment here, which is an initial option, is that individuals should be informed of the actual uses and disclosures of PHI. This notice should address disclosures of all other participants in the HIE, including third party intermediaries, etc. So, what do we think of this question?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I will note that that's what triggered me on the disclosure question before is that initial option language there about actual use and disclosure. So, forgive me for going down that path, but this is what led me there.

Deven McGraw – Center for Democracy & Technology – Director

Well, I get that, David. But the one thing about the existing accounting for disclosure requirement under HIPAA, which remains true even under the HITECH modifications, is that that only has to be produced when patients asked. So, I think this question gets more to what's the affirmative obligation with respect to patient education on uses and disclosures of PHI, regardless of whether it's asked for or not.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I want to clarify that earlier point. There are two ways to read the phrase "actual disclosure." One is to say the kind of disclosures the practice does as distinct from the broader set of disclosures that are permissible. The other interpretation is the specific disclosures were done about a patient. I actually started out assuming it was about specific disclosures and went back to assuming it was not about specific disclosures. It was about, of all of the permissible things that can be done, these are the ones we're doing. Am I misinterpreting that?

Deven McGraw – Center for Democracy & Technology – Director

No, I think you're interpreting it right on because otherwise, I think we do trip into the accounting of disclosures requirement and potentially risk turning it into an affirmative obligation to disclose to patients particular disclosures of that data, even if they haven't asked for it.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. I'm comfortable with the restriction. I just was trying to explain why I got sidetracked.

Deven McGraw – Center for Democracy & Technology – Director

I can understand that.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

What Wes is reading it better than the way I read it, so I'm happy with the limited focus.

Paul Eggerman – eScription – CEO

Maybe we need to wordsmith a little bit in terms of the actual use.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes.

Paul Eggerman – eScription – CEO

The word actual is where the problem is.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

So, I'll start the discussion just by saying that I think Paul queued it up perfectly well with the premise that the patient shouldn't be surprised. So if that's our common sense test, then I think the answer is the patient should be notified about disclosures that could happen that might be surprising to the patient, which isn't specific, but I think that's the rubric that would guide us. Things that you'd probably want to know about with respect to what's happening to your data that you might not automatically have assumed or guessed. So you assume the nurse down the hall has access to it, but you might be surprised to know that it's going through an OHCA to independent practicing physician in the community, for example.

Paul Eggerman – eScription – CEO

So, if I heard you right, David, one of the things that you would say is if the provider's record is hosted within an environment that—some people call it community record or it's hosted by an OHCA—and as a result, other providers or entities have access to that data, then patients need to be notified of that.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. I was really trying to make a broader point, which was not specific enough to turn into a concrete recommendation, but just to say the guiding principal is things that would surprise you if you didn't know about it. So I was thinking through this over lunch with a colleague of mine and just running use cases by and saying, "Would you be surprised if this happened? Would you be surprised if this happened?" It was pretty clear that it was easy to answer the question yes or no. What's really hard to do is to write a proactive definition of how someone would answer the question yes or no. I would be surprised. I wouldn't be surprised. But I think that the notion of that patients ought to know stuff so they're not surprised when data flows outside the provider through some kind of entity like an HIE or an OHCA, or for that matter, other arrangements that—even directed connect. I mean, it may be that we should—directed exchange, maybe they should be notified that that kind of exchange happens also.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'd like to suggest that that does a good job of reinforcing our mission, but doesn't help much in terms of determining what should be on the list. I'm going to channel Judy Faulkner for a minute here and say I can't imagine anybody whose lawyer is going to let them leave something off the list because it ought to be known.

Judy Faulkner – Epic Systems – Founder

Ah, Wes. Yes.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Also I think we are working with the description of the patient here that's something like the reasonable patient should be able to know this. I mean, who's expected to know what is kind of the question at hand. There are patients who may be at some extreme in terms of the normal curve of understanding of healthcare processes that we'd want to decide who we're trying to target.

Deven McGraw – Center for Democracy & Technology – Director

Right. Well, that concept certainly came up when we were thinking about our recommendations on where additional consent should apply. Again, it did presume the trust relationship between patient and provider, which we acknowledged was true probably in most cases but not in all. Then in terms of patient surprise, obviously there are always going to be folks that would be surprised by things that maybe wouldn't surprise most of us on the call.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I just want to clarify that the word reasonable, as I remember it in the consumer protection law, applies to the expectation, not the person. ... person, it's a reasonable expectation. Reasonable people is a much different—

Deven McGraw – Center for Democracy & Technology – Director

No, that's right. Well, it sometimes applies in both the person and the expectation but it's much easier to conceptualize in terms of whether it's a reasonable set of expectations.

David, I like where you're going with this, but it brings up a question in my mind, which is are we suggesting that only those types of uses and disclosures outside of an entity that would be reasonably surprising or unreasonably surprising need to be disclosed? Or is there a different test which is that basically patients ought to have a base—and this is in many respects, I'll admit it, tying questions one and two a little bit together. But is there an obligation to generally describe your trading partners in particular, who you disclose information to on a general basis, and then certainly those that would be surprising to patients, given the new environment?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. So, my comment was going to be sufficient to write it down. It was just reflecting we have a slippery problem here. What's the emotional guide, if you would? How do you decide? So if I were a provider who worked at hospital A. I got sick. I want to get cared for by people that I don't know really well. I go to hospital B. I get cared for there. The data from hospital B is shared through an HIE back to my colleagues at hospital A. Okay. That's something I'd want to know that that's going to happen. That would be a surprise to me. Now, if I'm a provider, presumably I would know those things. So, it's when the data crosses the boundary of the institution that I perceive is ... providing my care, then I'd want to know about that, regardless of whether it's an HIE or an OHCA or a directed exchange. It's crossing the boundaries of an organization that I ... sought care at.

So what is the boundary of an organization? I don't know how to define that, but that's kind of the emotional concept of when it's a surprise is when it crosses those boundaries. I go to the hospital. I know people in the hospital are going to use that information. What I didn't know was that people in the hospital across town had access to it also. Or what I would be surprised at if—

Paul Egerman – eScription – CEO

So are you suggesting that the policy recommendation is that we need to notify patients that if there are circumstances under which their electronic records may be accessed by other entities, and that's it. Maybe accessed by other entities or maybe accessed by other entities outside the course of treatment?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

You'll recall that the surprise principal, we really created with respect to when consent was needed. What we're discussing here is this notification. I think we have to be real careful that we keep those two

distinct. In going back to our previous policy recommendations, you're getting on the border of a shift of control. If they'd really be surprised about something, I think that our principle still stands. We ... their consent. I think what they are notified of is, yes, who are their general partners. I don't think they need to be named by name, but the kind of BA's that they may have, the kind of activities that they hire BA's to do; those kind of things should be in the notification.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I like what Dixie said because it was getting us over the immediate point. If we accept what David said that this is a notional idea that sort of helps guide our deliberations as opposed to we're going to really decide what is disclosed based on what's surprising and go back to the discussion of what should be disclosed, I think we can move along faster. I think that's what Dixie was doing in her comment.

Paul Eggerman – eScription – CEO

So, what is written here for initial options what we want to say?

Deven McGraw – Center for Democracy & Technology – Director

Is there a way to make the screen bigger? I also am looking at this on a laptop, and we're going to have to read it out anyway because we have people on the phone.

Paul Eggerman – eScription – CEO

Okay.

W

Also—everybody who's on the computer— if you press the full screen button at the bottom, you can see it a little bit larger, and then press full screen to go back to the original layout.

Paul Eggerman – eScription – CEO

Okay. Let me read it also. It says, "Individuals should be informed of the actual types of uses and disclosures of PHI. This notice should include disclosures to all of the participants in an HIE, including third party intermediaries, OHCA's, etc. as appropriate."

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Would that mean that they had to list all the participants in the HIE?

Paul Eggerman – eScription – CEO

No. The way I read it is you would simply say something like, "Your data will be sent to the New England Health Exchange Network."

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I would also add something like, "Various business associates that perform services for us." I don't think it's reasonable to expect these entities ... specific business associates that they may have, specific participants in the HIEs. I don't think that really provides much value anyway, but I do think they should mention that, "Yes, we have various contractors who perform services for us," or whatever.

Paul Eggerman – eScription – CEO

Yes, I think the various contractors, though, are in a separate bucket, Dixie.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Those are business associates.

Paul Eggerman – eScription – CEO

Well, they're business associates but it's not necessarily information exchange. In other words, a provider might use a business associate to do mailing services for them and that's not information exchange. I think if you think about large organizations like Intermountain Healthcare or UPMC. I mean you're talking about possibly hundreds of organizations.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

That's what I'm saying. I would not list them out, but if they use business associates in information exchange, I would say—what she has here—various business associates.

Paul Eggerman – eScription – CEO

Business associates involved with information exchange.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

... you're concerned about is not broaching over to the general HIPAA disclosure and staying focused on information exchange.

Paul Eggerman – eScription – CEO

Yes. We need to stay focused on information exchange.

Christine Bechtel – National Partnership for Women & Families – VP

Well, Paul, two things. If I can jump in and just say one of the biggest areas that patients have concerns about or at least they're very surprised by when they find out after the fact is research. So do you consider that information exchange?

Deven McGraw – Center for Democracy & Technology – Director

No. We consider it outside of stage one of meaningful use.

Paul Eggerman – eScription – CEO

Yes. It's a topic we haven't addressed yet. It's a good topic, but it's not one we've addressed yet.

Christine Bechtel – National Partnership for Women & Families – VP

I guess what I was getting at is that what is more meaningful to patients is not the "who" but what's the purpose.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes. I agree.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I think one minor bit of tuning—I don't think various business associates adds a wit of value to this without some way of at least pointing to a list of them and I'm not suggesting that. I do think that for HIEs, it would be possible to say, "Identify the HIE."

Paul Eggerman – eScription – CEO

That gets to question number two, which is the only reasonable thing.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'm always skipping ahead.

Paul Eggerman – eScription – CEO

You're 100 miles ahead of us, Wes, as always. We appreciate your future.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'm precocious.

Paul Eggerman – eScription – CEO

So, I just wanted to sort of stick with this. I'm confused. Various business associates involved in information exchange. Is that in or out of this?

Deven McGraw – Center for Democracy & Technology – Director

It's interesting. I get that it doesn't feel very much of value. I think the thing that I'm still struggling with in my mind is the statement that David made about what's probably of most concern for people is when the information breaches the boundary of the organization.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Don't use the word breach.

Deven McGraw – Center for Democracy & Technology – Director

Oh, yes. You're right. Okay, crosses. Good point. Crosses the boundary of an organization, that that likely ratchets up the concern level and is of more interest to people. But on the other hand if what they're getting is we share it with our business partners who are performing services on our behalf, there's not a whole lot to that. So maybe there's something that can be done in that regard with respect to purposes. But even there, and I'm just playing this out a little bit, we share with our business partners so that they can help us submit your claims or they can help us to credentialing for the physicians on our medical staff, etc. It still feels like it's not a whole lot, although it's an interesting picture of the different ways that data is shared.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I had reason to go to the hospital about a month ago on a routine colonoscopy, but while I was there, I was offered and I chose to accept for the first time ever, their notice of privacy practices, which is a lovely, wonderfully written book. It's 13 pages of information listing all of the potential entities to which my healthcare data may be disclosed, including an entity that they call third parties, which is the business associates, but there's literally a dozen other entities that are already accounted for under HIPAA. What's strikingly missing as I read through this now, is there's no mention whatsoever of the fact that this hospital participates in a local RHIO; in a local HIE.

Paul Egerman – eScription – CEO

Isn't that what this—?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. So I think what we're trying to do is say that in addition to what they currently disclose under the NPP, these other entities like HIEs and OHCAs should be added to the list. But I think things like business associates are already in the NPP.

Deven McGraw – Center for Democracy & Technology – Director

Although actually, David, that sounds like a notice that goes above and beyond the law because you're not technically—and, Adam, please correct me if I'm wrong—but I think I've always read the privacy rule is requiring you to include in your NPP the legal permissions and restrictions on your use of data but not what you actually do. It sounds like this hospital actually gave you a snapshot, albeit at a broad level, of what they actually do, and as a result, it's a 12-page long notice.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes. They mention disaster relief, notification of clergy, communication barriers, appointment reminders, treatment alternatives, media stories, third parties. I mean, there's a long list of things that probably do beyond the letter of the law, but they don't mention HIEs.

Adam Green – Progressive Chain Campaign Committee – Cofounder

I can just clarify that most on that list is required pursuant to hard notice requirements, so you are required to list healthcare operations. You're required to provide an example of treatment, healthcare ops and payment. Then for other things such as law enforcement, traditional ... potential judicial hearings, you're required to list them but not provide an example. We have a few specific provisions like appointment reminders that are in there. We don't require any reference to business associates to be in there, and we don't—as Deven, you've indicated—require you to make any distinction between what you may disclose versus what you actually user disclose. We don't have anything with respect to health information exchange.

Judy Faulkner – Epic Systems – Founder

Do you have any specific on how many people read it?

Deven McGraw – Center for Democracy & Technology – Director

There's actually a lot of literature, Judy, on people reading notices and how many read them and how many people understand them. It's unfortunately a bit of a dismal story.

Judy Faulkner – Epic Systems – Founder

Yes, because I was thinking if we're going back to patients not surprised, the most effective thing I've seen I think is in ... where it just simply said we share your data with everyone involved in your care. It says it in a better way than I've said it, but if I'm a patient, doesn't that give me—

Paul Eggerman – eScription – CEO

Can you speak up a little bit? I'm having trouble hearing you.

Judy Faulkner – Epic Systems – Founder

I'm sorry. I'm not usually on a— Does that help?

Paul Eggerman – eScription – CEO

Yes.

Judy Faulkner – Epic Systems – Founder

Well, I think that the more detail we get, the more we're going to run into we will have surprised patients. So aren't we in the end going to be best served by crafting something that allows the patients to understand what it is? Then if they want to go at a deeper level, I don't know what to do about that, but I don't think people are going to read the deeper level. So what is the purpose of it then?

Adam Green – Progressive Chain Campaign Committee – Cofounder

We do have, in the preamble to our 2002 modifications to the rule, we mentioned the idea of a layered notice as something that people may want to consider, where you have more summary information as kind of a top layer and then more detailed information at another layer so that people can just look at a summary of their rights and some of the general uses and disclosures. So that's something that we've thrown out as permitted and something that people may want to wish to consider.

Judy Faulkner – Epic Systems – Founder

I think the thing is once it's on one big piece of paper that is, even if it has a summary at the top but goes on and on, I'm just going to get to end of it and say, "Where do I sign?" I think most people are. That's why I think something separate from that that is not in, "Where do I sign?" places, but it's like a no smoking notice. I see a no smoking notice.

Paul Eggerman – eScription – CEO

Those are good comments. I think we're going to get to those comments in questions two and three, in terms of how we structure this notice.

Judy Faulkner – Epic Systems – Founder

But the more we have that's required to be in it, the more defines how the structure is.

Paul Eggerman – eScription – CEO

Yes, that's right. So we need to decide what it is because it is a case— There's a lot of analogies. So it's like, companies that are publicly held, non-profit organizations have to publish a detailed financial results, and most people don't read that stuff, but some people do. A lot of people rely on the people who read it, right?

So, the same is true of all of the privacy stuff, right? You get privacy information about some site on the internet, most people don't read it. But you hear the privacy experts think that something is done poorly. You sort of rely on somebody else to tell you. So the purpose of transparency is not necessarily to tell

everybody everything. It's just that the information is available. Then we've got to think about how we make it available so we don't annoy people and we don't create burdens.

Judy Faulkner – Epic Systems – Founder

If that's what you think should be it, Paul, then I think you have to change how you started this meeting, which is no one should be surprised because now what you're saying is those who are interested in looking deeper can find it out. But it isn't that no one will be surprised because this is the way that we know, people will be surprised because they're not going to read that

So I think we have to figure out what we're doing. Do we really want no one will be surprised then how do we not surprise them? I don't think this is the method. Then I think we'll really have to separate each piece—OHCAs, business associates, and interoperability to direct exchange, interoperability through RHIOs, so that we're understanding what are we really trying to get at.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Not disclosing it doesn't reduce surprise. I mean, if unexpected exchange occurs, you're surprised regardless of whether the notice was short, long, layered or not.

Deven McGraw – Center for Democracy & Technology – Director

Yes. I think we have to be careful not to take the patient expectations list as an absolute ... test. But I do think Judy raises a good point that the more you increase what's in the notice, you always have, unfortunately, the potential impact that people will be less likely to read it. But I suggest that we—because these questions are all inter-related, but let's put down some draft answers to the questions. Then we can see if they fit together as a whole.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

After Paul was just talking, it occurred to me that what you're really looking for is a delta between what is currently required by law and what should be added based on these information exchanges. Is that correct?

Deven McGraw – Center for Democracy & Technology – Director

That may be one way to frame it.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

That makes sense to me.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

If that's so, then I would say that first sentence is duplicative of what already is included. "Information should be informed of actual types of uses and disclosures of PHI." That's already the case. So we should be really focusing on these exchanges.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

... the case.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

You could say something like, "In addition to notices required under the current law be additional blah, blah, blah."

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes.

Paul Egerman – eScription – CEO

Right.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

What we're really hoping for.

Paul Egerman – eScription – CEO

That's correct. The formula Judy said which is separated out information exchange, HIEs, or HIOs from the OHCA and the business associates I think is also useful. So, I think what you really want is notice if a provider is making information available to or through an HIO or other ... service organization, right?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I would go a step further and say the identities of the HIOs through which the provider is currently—

Paul Egerman – eScription – CEO

Yes. I think ... to question two, but I agree.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes. I agree.

Paul Egerman – eScription – CEO

So, you just want to say— And I suspect we're going to want some at least brief description of what it is. But anyway, we're going to talk about the HIO as it relates to the OHCA. Don't we want to say something like, "If the provider participates in an OHCA," say like UPMC or partners, "and as a result, the patient's medical record with that provider is going to be available throughout or to some of the other users in the OHCA," that accessibility needs to be disclosed.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

So, is that part of our charter, or is that just a general—?

Paul Egerman – eScription – CEO

It's a good question, Wes, but it's a little bit of unfinished business from our consent discussions because we said, "Well, OHCA's don't count." Somebody said, "How do you know?"

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

It seems to me the whole definition of an HIO— So we said an OHCA is not an HIO, is that right?

Paul Egerman – eScription – CEO

That's correct. An OHCA cannot be an HIO. An HIO cannot be an OHCA, I think, is a better way of saying it.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, that's right. That's it.

Adam Green – Progressive Chain Campaign Committee – Cofounder

There's a provision in our notice about OHCA's that may be worth mentioning, which is that if you participate in an OHCA, you are allowed to do a joint notice, so a single notice for the entire OHCA, which describes with reasonable specificity the covered entities or class of entities to which the joint notice applies, describes with reasonable specificity the service delivery sites or classes of service delivery sites to which the joint notice applies, and if applicable, states that the covered entities participating in the OHCA, will share PHI with each other as necessary to carry out treatment, payment, or healthcare operations related to the OHCA. So, that's optional. Basically, covered entities participating in an OHCA can have their own separate notices or they can have a single OHCA notice that details if they're involved in an OHCA.

Paul Egerman – eScription – CEO

That's good, because I picture this as the small community private practice that decides that they want the medical record hosted by some regional healthcare organization. It's great if they can use, besides having them host it, if the regional healthcare organization says, "Here's the paperwork too. You don't have to create your own notice."

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'm glad we don't have to discuss that because that would certainly not meet Judy's test about being— I mean it fits into the category of too big to be read, right?

Judy Faulkner – Epic Systems – Founder

Yes.

Paul Eggerman – eScription – CEO

That's right.

Judy Faulkner – Epic Systems – Founder

Not only that, it probably changes every other week.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

The question, I think, is do we need to include OHCAs in our disclosure discussion? What I hear from Adam is that there's already really specific guidance about disclosures about OHCAs elsewhere in the form of this common disclosure guidance.

Adam Green – Progressive Chain Campaign Committee – Cofounder

Right, although it's optional. It's not required.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, I think we might want to include it anyway on the recommended.

Deven McGraw – Center for Democracy & Technology – Director

At least to underscore it or suggest that it ought to be—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

We could say if not covered elsewhere— We certainly don't want it to get left in the cracks between two different focuses of attention.

Deven McGraw – Center for Democracy & Technology – Director

Right.

Paul Eggerman – eScription – CEO

Then what about this issue about various business associates involved in health exchange? I'm a little bit worried about that as it relates to Judy's—

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think that's already covered under the standard required notice, so I would say we don't need to mention that.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes, I was going to say, it doesn't do anybody any good except the lawyers.

Deven McGraw – Center for Democracy & Technology – Director

It doesn't even do the lawyers any good. It doesn't have any details.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Oh, okay.

Paul Eggerman – eScription – CEO

So we're going to drop the various business associates.

Deven McGraw – Center for Democracy & Technology – Director

Again, I think if you've got already in the notice a lot about what they're permitted to disclose and that includes to business associates without—as much as I want people to have a more complete understanding of how their data is shared, it's not of a lot of value to just say, "We share it with business associates," ... providing details.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Right. Paul mentioned a point that I think is worth re-tweeting here, which is there are really two audiences. One audience is the, pardon the expression, reasonable patient. The other audience is the advocates for the reasonable patient or advocates for the patient. I think we do need to be pretty clear about addressing the needs of both communities. I have a sense that for most advocates, listing the permissible disclosures doesn't add much value. That is, they already know what the permissible disclosures are. I just think we have to somehow deal with Judy's really important issue of making the disclosure effective and also think of the advocates at the same time.

Paul Eggerman – eScription – CEO

I agree. But the first part is to decide what it is that we're going to notify patients of.

Judy Faulkner – Epic Systems – Founder

Yes, and I think to take it back one step from that, we have to decide is it more that we're trying to alert patients and notify them? Or is it more that we're trying to be legally covered?

Deven McGraw – Center for Democracy & Technology – Director

No, the former, Judy, I think.

Judy Faulkner – Epic Systems – Founder

Then I think we have to be very careful how we do it, then.

Deven McGraw – Center for Democracy & Technology – Director

Yes. Absolutely. Here's a suggestion, Paul, is that we actually try to move to some of these other questions, which are pertinent to the issue of what we actually want disclosed. Because I think from an ideal standpoint, again, I think we want people, patients in general, to have a better picture of what happens to their health data. But then we're struggling with this concept of the notice because we know the more we shove in it, the less impact it has.

Paul Eggerman – eScription – CEO

Okay. The second question is what should be the required level of disclosure? In other words, how much detail should be provided? So if you want to say you participated in an HIO, do you have to say the name of the HIO? Do you have to describe it's federated versus centralized? Do you have to say here's a whole boatload of stuff about it? Do you have to give a link to the Website of the HIO? What do you have to do there?

Deven McGraw – Center for Democracy & Technology – Director

Well, I think on the centralized HIO, I think we put a lot of information in our meaningful consent recommendation about what patients need to understand because that's a consent situation.

Rachel Block – New York eHealth Collaborative – Executive Director

Yes, that was actually what I was going to say. I know we aren't talking about consent today, but it really is more meaningful, I think, in the context of the consent process to know who would have access. Again, going back to one of the other points, the names and types of participants in the HIO will change on a regular basis. I think that it would be far more effective for the notice to reference the availability of information through a Website or some mechanism like that and not get into these details.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I wonder if the disclosure notice from the provider to the HIO is one thing, the disclosure notice from the HIO to the consumer about what the HIO allows to happen to that data is something different?

Paul Eggerman – eScription – CEO

Yes, but we're talking about the provider to the consumer, the provider to the patient. So our focus is not on the HIO to the patient.

Deven McGraw – Center for Democracy & Technology – Director

It's not, but I think our ultimate focus is on getting patients information. So I think if we're in fact saying that the provider shouldn't bear all of this responsibility, the HIO should, I think that's relevant.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

So I was just saying that if the provider says, "We participate in Heartland Health, but I'm not sure which other hospitals participate, you'll have to ask them." I think that's a reasonable response from the provider.

Paul Eggerman – eScription – CEO

I agree.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

That was the point of making the distinction was I don't think the provider should be required to list the participants in the HIE.

Paul Eggerman – eScription – CEO

But do you think they should be required to list the HIE or the HIO?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes, I do.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

What law requires an HIO, since they'll be a business associate, to issue a notice of privacy practice?

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I thought that ... made them have to do that.

Deven McGraw – Center for Democracy & Technology – Director

No, they don't have to do everything in the privacy rule. If their business associate agreement makes them do it, then they do. That actually could be an area of recommendation.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I think David's recommendation makes sense but I think we do need to recommend that they provide that; that the HIO provide that.

Micky Tripathi – Massachusetts eHealth Collaborative – President & CEO

It seems that we also need to distinguish or make clear that it's not about the HIO as an organization. It's about whatever function they're performing because an HIO who is just performing directed exchange of an intermediary, for example, we already said that they don't need any of this. Correct?

Deven McGraw – Center for Democracy & Technology – Director

Right. Well then, they're just a business associate, right?

Micky Tripathi – Massachusetts eHealth Collaborative – President & CEO

Right.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Well they're always just a business associate, but Micky made a good point because going back to what David said, if a provider said, "I use Micky's HIO and go there to find out what their privacy practice is," but the provider only uses that HIO for directed exchange, that privacy practice of the HIO may not be meaningful to the patient.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

But the HIO could explain that and say, “I’m merely facilitating directed exchange. I’m not exchanging data with any other third parties.” That’s a valid answer.

Deven McGraw – Center for Democracy & Technology – Director

That could possibly be on a per patient basis, right? I mean—

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Yes.

Deven McGraw – Center for Democracy & Technology – Director

... patient who did not give meaningful consent to having their data exchanged through a model where we have asked for meaningful consent to be applied and the provider can still exchange directly and use the services to do so, but then for the patient to be sent to the HIO, the HIO may not necessarily know that particular patient’s circumstance.

Paul Egerman – eScription – CEO

So, the way to address this to say for those entities that trigger consent, the notice needs to name those entities and provide information to the patient where the patient could obtain additional information about how those entities use their information?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I go again to since that HIO ... David in indirect example, where you could have an HIO offering two different services—the transformation or the directed exchange—and a provider can buy only the directed exchange service, right? So if the provider buys only the directed exchange service, there needs to be some mechanism for the patient to know that that’s all that’s happening to their data.

Paul Egerman – eScription – CEO

Okay. So, I said it needs to be wordsmithed, but for those activities that trigger consent, the notice should name the intermediary entities involved and provide the patient with information about how he or she can find more information about those entities, if they choose.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I think the first part of what you say is correct. For those activities that trigger consent, that they need to name specifically the intermediaries they’re using. But I think they also have to name the services they’re buying from those intermediaries.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I have to say that when it gets to making things obscure for patients, that that gets there pretty fast. The purpose to which they’re putting the connection with the itinerary comes close to at least being user-comprehensive or patient-comprehensible, I think.

Deven McGraw – Center for Democracy & Technology – Director

What do you mean, Wes? I didn’t understand that.

Paul Egerman – eScription – CEO

I didn’t understand that either.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Well, I’m going to list the NEHIN directed update service. What does that mean to a patient? What’s the difference between that and the NEHEN information exchange? I think that the services that the HIOs offer are bordering on the ... for physicians much less patients. I think they need to know, so I’m trying to trace down—

There's two things going on here. One, we're trying to get people how not to be surprised. Two, we're trying to give them a clue how to learn more about it if they want to. It's not clear to me that we can do that much when it gets to listing the specific services unless they're some sort of broad characterization of what the services are about.

Deven McGraw – Center for Democracy & Technology – Director

Yes.

Paul Eggerman – eScription – CEO

Would it be responsive to your concern if we determined those broad characterizations? If it was the patient's access by other providers—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I think it would be—it might be. I think we have a problem there of sort of the specificity that we get to versus the durability of our recommendation as concepts change. But certainly, I think just listing the trade names of the services that are available from HIOs is not helpful. Trying to come up with a really specific set of categorization is that ... madness. So—

Deven McGraw – Center for Democracy & Technology – Director

What about a general description of the functions of the HIE that don't get into specific services?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Well, that's what I sort of meant by purpose. I'm doing this through this organization to send results to other providers or to send reports to other providers involved in your care. That is a way of arriving at broad categories of services that is relatively comprehensible to the patient.

Paul Eggerman – eScription – CEO

So the set of services, you said, the services they provide, so really the purpose of the services that they provide.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'm trying to be responsive to a suggestion about listing the HIOs and their services, okay?

Paul Eggerman – eScription – CEO

... and the services they provide.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I have a suggestion.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Instead of services, saying purposes I think is—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Given that we're only talking about the use of those intermediaries whose use triggers consent, right, so we already have eliminated any HIOs that are just directed exchange HIOs. It may not be even necessary to say the purposes because it would always be something that they would have access to their health information.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

If we were ... we would just call this the complement of directed exchange.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

I think what we need to do is name it. Deven and I had an offline conversation and I wanted to call it indirect exchange and she shot that down for good reasons, but in the universe of information exchange, we have carved out a well-defined directed exchange. What we're now talking about is the other stuff. So what do we call it?

Deven McGraw – Center for Democracy & Technology – Director

I'm trying to pull our Tiger Team letter on what we actually said was needed for meaningful consent to see if we gave any more detail on the transparency point.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Oh, good point.

Deven McGraw – Center for Democracy & Technology – Director

I don't know that we did.

Christine Bechtel – National Partnership for Women & Families – VP

In terms of trying to define categories of purpose, if our context is only meaningful use stage one, that's a fairly limited universal purpose, right? I mean, couldn't we—unless I'm off here—pull the matrix then and say, "Okay. These are the areas that we think we can imagine exchange and, during stage one which is a limited time period." And then ... on stage two or three later?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Well, I think we're coming to the point where we may not even need to come up with these purposes. If we come up with a term, as David suggested, suggests—

Deven McGraw – Center for Democracy & Technology – Director

Well, what? Calling it indirect exchange?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

No, calling it something.

Deven McGraw – Center for Democracy & Technology – Director

Yes, but what does that mean in terms of openness to patients? I'm not following.

David McCallie – Cerner Corporation – Vice President of Medical Informatics

Well, I think the notion is that one way to make this more understandable is to give it a name that can be defined and looked up and in reference to. If we have to continually refer to it as those services which aren't direct, it just makes it

Deven McGraw – Center for Democracy & Technology – Director

Well, right, but we still have to define them in a way—

Paul Egerman – eScription – CEO

Let's leave the naming issue as a side issue. I want to see if we can answer this question. So, what I'm saying is whatever we call it, those activities that trigger consent, we're saying a notice should name the intermediary entities involved and the purpose of the services they provide, and provide any additional information about how these ... and provide patient with—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Reference to.

Paul Egerman – eScription – CEO

...references so additional information can be obtained. Okay? Now, for this additional information, one question I had is we made this recommendation that the business associates have to disclose a bunch of stuff to the providers. So, for example, maybe the business associate discloses that their data retention

is they keep all records for 20 years. Is that something that patients need to be notified? Is that part of this notice, or is that—? What do we do with that information?

Christine Bechtel – National Partnership for Women & Families – VP

But again, maybe I misunderstood, but isn't our context only meaningful use stage one, because that was the answer when I raised the research question. Document retention is not part of meaningful use.

Deven McGraw – Center for Democracy & Technology – Director

Yes, but they might retain a document to facilitate any of the functions of stage one. But I also don't think—I mean retention of data is an issue we addressed in fair information practice.

Paul Eggerman – eScription – CEO

I didn't mean to start a discussion on retention of data. I was trying to link what we're saying here to that other recommendation. Whereas the provider has information about those HIOs are doing, to what extent is there an obligation to tell patients whatever information the provider already has?

Deven McGraw – Center for Democracy & Technology – Director

I guess I think, ideally, the patients should be provided with a general description of the purposes for which the HIO can use data and then a link or a reference and contact information for the patient to get more information such as who's participating, what are the details about their data practices and policies.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes. That's good.

Paul Eggerman – eScription – CEO

Okay. Is that pretty much what we tried to write down here? For those activities that trigger consent, the notice should name the intermediary entities involved and the purpose of the services that they'll provide and provide patients with references where additional information can be obtained.

Deven McGraw – Center for Democracy & Technology – Director

Right. I think I would say name the intermediary entities involved, general description of the services provided, and then—

Paul Eggerman – eScription – CEO

The purpose of the services.

Deven McGraw – Center for Democracy & Technology – Director

Right.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

The only thing there that's still needed is some policy that requires that that intermediary provide that additional information to patients, because we have no—

Deven McGraw – Center for Democracy & Technology – Director

Yes, that's right. We did say that. We haven't noted that yet. It kind of doesn't fit in this box, but we need to note that so that it shows up in the recommendation. We'll pull the transcript.

Micky Tripathi – Massachusetts eHealth Collaborative – President & CEO

I'm wondering if there's an overarching principle—and tell me if there's not—about plain English, or something like that. I don't know whether there are any sort of legal guidelines or guidelines that speak to things being in plain English versus technical language. When we launched Health Information Exchange in Massachusetts, we had a ... consultant who was asking very explicitly, "Do you want this at the 6th grade reading level, 8th grade reading level? There seemed to be a term of art kind of framework that she was using, and I'm just wondering whether I'm certainly not the first one to consult this.

Deven McGraw – Center for Democracy & Technology – Director

Well, and there's language issues too, so I know you have to, Adam, have to be in plain English from HIPAA standards, right?

Adam Green – Progressive Chain Campaign Committee – Cofounder

Correct.

Deven McGraw – Center for Democracy & Technology – Director

But reading levels aren't specified, and what about language? Common language as spoken by the patients and disability issues?

Adam Green – Progressive Chain Campaign Committee – Cofounder

We specifically state that the covered entity must provide a notice that is written in plain language. We don't have any specificity as to the reading level. While the privacy rule doesn't address different language requirements, there are other relevant laws that fall under ... Office for Civil Rights that would require that you accommodate multiple languages.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I just want to say that I'm a little worried in that last iteration of the language that we are basically undoing our previous recommendations where we decided that the conversation between the provider and the patient was an important conversation. That that couldn't be delegated to a third party for the patient to understand the basics of how their information is being shared. The way I heard the last recommendation, it was, "Oh, and we participated in this exchange. Go to them if you want to find out what that means."

I think at a minimum, the notice should include not just the party that's addressing information sharing, but the circumstances under which their information will be shared and who will make the decision about that. In other words, I don't think we meet the surprise test with the current language.

Deven McGraw – Center for Democracy & Technology – Director

I think you're right, Carol, that we're going to have to wordsmith it, but it's always a struggle to do that on the phone. As Paul mentioned in the very beginning of the call, given that we now only have calls on a two-week basis, we're going to try to more vigorously use our offline abilities to try to wordsmith this stuff. I think we need to try to make sure that this is consistent with what we've said previously.

Paul Egerman – eScription – CEO

Also this business about the intermediaries need to provide this information, there's a way to make that consistent, which is we said the providers are responsible. We did say on some circumstances, they could delegate responsibilities and also that it was reasonable to expect the intermediaries and other organizations, including the government, to provide materials to assist them. So, we could sort of reference them and say providers are responsible, although they can choose to use information and reference material that the intermediaries provide. In which case, I think we're accomplishing what you're saying, but at the same time, we're not putting a burden on the providers because under those circumstances I'm sure the HIOs would provide that information. Otherwise, providers won't use them.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Well, I think assuming that the exchange is going to have a one-to-one conversation with the records that are transacted by them is a tall order if we're relying on that as the way to inform patients. I guess I would go back to what David said at the top of the call, which is if I end up at hospital B and I'm surprised that my information is there also. I don't know that the current wording really prevents that.

Paul Egerman – eScription – CEO

I wasn't suggesting a one-to-one conversation, Carol. I was suggesting that the HIOs could do different things. They could give them booklets to hand out, for example, or a Website or something that provides more detail.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

I would make my same point.

Deven McGraw – Center for Democracy & Technology – Director

Yes. I do think we need to work on this language a little bit. It's always a little bit rough and I'm sure the poor folks from MITRE might not necessarily fully understand what we're grasping at here, and we may not have completely coalesced around it. So we're going to have to do some offline—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Just to be clear, we are placing a responsibility and accountability on the provider to give patients information that would prevent them from being surprised under reasonable scenarios. We're dealing with all kinds of pragmatic and practical quantitative issues about how much that is. I really heard one more thing from Carol that I wanted to verify, that we expected this to be a conversation between the physician and the provider? Between the physician and the patient?

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Certainly for information sharing there is a conversation that happens, particularly if the physician is talking to the patient about sharing their information electronically. I would argue this happens in the paper world today as sort of a custom practice where when there's a release of records, the patient is ..., "If you want your records to go to such and so provider, you have to sign this release of records." So there's something in the analogue world that happens today that makes it clear that records are shared.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes, I'm not sure the physician says that. I mean, if I go to my hospital and say, "I want information released," it's not the physician that tells me I—

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

That's fine. It doesn't have to be the physician. We could use the term loosely, "provider," but something happens at that point of interaction with the patient.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Okay. So in the case of HIE, we generally don't believe the patient will be there at the exact point of interaction, so we're trying to anticipate that. We're trying to do it on a manner that's similar to disclosure where we let the patient know in advance at a sort of convenient point in the set of interactions around the patient—and stop me if I'm going astray here.

We are saying that the level in this balance between disclosing so much it's useless and so little it's useless, we're trying to find a place in the middle that's not useless and if—I didn't want to say it's useless, but in that balance, it's important not to do too much of, "Well, it's going to happen here, but you've got to check with them. It's got to happen here, we've got to check with them." So, somehow we're trying to find a reasonable amount of disclosure that is in that interaction between the provider and the patient without overwhelming them with detail or creating something that has to be updated too often.

Carol Diamond – Markle Foundation – Managing Director Healthcare Program

Yes.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes. Okay, thanks.

Paul Egerman – eScripton – CEO

So, this is an interesting discussion. I'm trying to figure out how we're going to take—

Deven McGraw – Center for Democracy & Technology – Director

Where we're going to go.

Paul Egerman – eScripton – CEO

Where we're going to go. Let me propose something, which is that Deven and I need to write this up and circulate it with everybody. Then we need to sort of look at the total picture of the questions that we're not going to get a chance to go through in detail, though Deven might want to take them through very briefly to see if, as a result, we can sort of synthesize some comments perhaps through an e-mail discussion prior to the next meeting.

Deven McGraw – Center for Democracy & Technology – Director

I think you're absolutely right, Paul, because we're also running out of time. I think it also may be the case that because of the complexities involved here that Wes just really articulated well and that other members of the Tiger Team have raised, we may not be dealing with a good situation where there's a one-size-fits-all approach. That instead we need to think about some sort of general obligations and considerations and to whom those obligations would apply, but without saying thou shalt do X and thou shalt do Y. That may not be easy enough to understand because I sort of haven't fully formed an example in my mind, but—

Paul Eggerman – eScription – CEO

Well, the hard part here also is we're trying to do a good job. So that makes it harder. I use this as an example. You look at, like, SEC disclosures, which I think is very important for publicly held companies. But you've got these sort of mammoth disclosures. It's like administratively difficult and burdensome and there's good reason for it. But what we're trying to do is we're trying to say—well, we're not trying to say, "This discloses absolutely everything and that's good transparency." I shouldn't use the word disclose. We're not saying notify patients of everything and that's good transparency, because we're also meaning that's probably bad transparency. So the hard part is to find out exactly what Wes said; how to make sure it's not too little and how to make sure it's not too much.

Deven McGraw – Center for Democracy & Technology – Director

Yes. Tall order. A couple of the other subsequent discussions get to the notice issue, which we sort of talked around the edges about on our call here that it's not effective to jam a whole lot of information into a piece of paper so that, as David described it, patients are getting a book. Instead of something there's a chance that they might actually read it.

Are there other techniques of value for transparency? I think Carol raised one which is the conversation. Are there others? If people have ideas in their intervening days that we have before our next call, it would be helpful to hear. One thing that occurs to me now as I'm talking is that there is the educational program that the Office of the National Coordinator puts on which is required by HITECH—actually, it's OCR, I think, that does the educational program on privacy, and that would not get to issues of specificity of disclosures by a particular provider, but is an opportunity to educate the public at large about how the healthcare system works and data sharing in general. So that's another thing I'll put out there, but definitely would take some additional thoughts on that if you've got them.

Then the last question was about effectively accounting or measuring transparency. This may just be one that we just don't have an answer for, but it occurred to me in including this question that if meaningful use is a potential policy lever down the road for enforceability or accountability on some of what our recommendations are, is there something unique that we can offer in this category? So, don't forget to read your e-mail, I guess, is the bottom line and we'll be back to you on this.

The only other thing we had on the agenda was just to give a heads up that the next topic is—we've got John Lumpkin, who is the Chair of the Governance Workgroup, teed up to be on our call. I'm sure Mary Jo Deering, who is the primary person from ONC who's staffing that effort, will be on, and then of course we have some overlap in membership; Carol Diamond being specifically listed here. But there may be others. I don't have the list in front of me. We will of course probably have to do a little clean up on this transparency discussion, but we're going to try to get as much of it done, to try to reach some moments of clarity in the intervening days.

Paul Eggerman – eScription – CEO

Yes, and so do we need the full two hours for the governance discussion? We will be able to take a half hour or an hour to try to wrap up the transparency discussion?

Deven McGraw – Center for Democracy & Technology – Director

Yes. I mean, I think we're going to have to.

Paul Eggerman – eScription – CEO

Okay.

Deven McGraw – Center for Democracy & Technology – Director

Yes. Okay. I guess, once again another two hours went by in a flash.

Paul Eggerman – eScription – CEO

Very good discussion. As I say, it would have been a lot easier if we hadn't said that we wanted to do a good job, if we just said inform everybody of everything.

Deven McGraw – Center for Democracy & Technology – Director

Right, but I actually—

Paul Eggerman – eScription – CEO

The pressure of trying to get it right is—

Deven McGraw – Center for Democracy & Technology – Director

Is the hard part.

Paul Eggerman – eScription – CEO

Is the hard part.

Deven McGraw – Center for Democracy & Technology – Director

Well, but on a number of occasions, we referred to recommendations that we had already done, and I know that, Paul, when you and I try to work through this, I'm definitely going to rely on that. So I'm hoping that all of our hard work where we set the bar so high for ourselves will help us continue to reach a good conclusion on these issues as well.

Paul Eggerman – eScription – CEO

I'm sure it will.

Deven McGraw – Center for Democracy & Technology – Director

So I think we need to open it up for public comment, Erin.

Operator

We do not have any comments at this time.

Paul Eggerman – eScription – CEO

Well, thank you very much, Erin, Erin is standing in for Judy Sparrow who's attending a wedding today, and did an excellent job, so thank you very much, Erin. Thank you to all the members of the Tiger Team, and if there were any members of the public listening, we appreciate your participation also. So thanks a lot and have a good weekend.

Public Comment Received During the Meeting

1. Too little time for me to dial at end after listening on computer. I have been trying for some time to discover if the ONC is aware a developing technology called patient controlled encryption I have link for the paper on this. The current security and privacy designs implemented by vendors do not have my confidence and I believe will ultimately fail. I have linked to paper describing why (short 800 words). It is hard to think of a single issue raised by security concerns and FIPs that is not potentially better and more simply served by PCE. You have state your future work will "need t address the role of technology in protecting privacy and security". I hope the ONC will use the SHARP program to explore PCE. If it works we will be in a much better position. Will you do me the kindness of letting me know if the ONC is aware of PCE, and if so, where it stands in the ONC's plans? Thank you.

10. Nice discussion about a standard that the "patient should not be surprised." Can we get someone to write that down in the recommendation box?